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ABSTRACT

An exploratory study was conducted on the implementation of Part H of Public Law 99-457, with emphasis on the involvement of health care providers. A series of 10 focus group discussions were held with health professionals (mostly nurses and physicians) in five states (Colorado, Hawaii, Maryland, North Carolina, Ohio). These health care providers identified the role of service coordinator as the key to a family's successful entry to and maintenance within a family-oriented system of multidisciplinary services. Three models of service coordination varying by the degree of severity of the child's need for services were suggested. These included: (1) the physician as coordinator (usually for more severe impairments); (2) physician as medical coordinator with another professional coordinating services from other agencies and programs (the most prevalent model); and (3) physician as consultant to a multidisciplinary team (for cases where the disability is mild or less medically complex). Recommendations include examination of state directives related to service coordination for severely impaired infants and toddlers, specific allocation of funds for the position of service coordinator, and statewide planning for systems of service coordination. (DB)

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SHORT REPORT

Carolina Policy Studies Program
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PROVISION OF SERVICES TO INFANTS AND TODDLERS WITH DEVELOPMENTAL DELAY: THE HEALTH PERSPECTIVE ON THE ROLE OF SERVICE COORDINATORS

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Introduction

The following paper on the role of service coordinator from the health perspective emerged from an exploratory study conducted by the Carolina Policy Studies Program (CPSP) on the implementation of Part H of IDEA (formerly P.L. 99-457). The focus of this study was on how health professionals provide services to children with disabilities and their families. A primary proposition in this study was that involvement of health care providers was critical to a system of services developed to implement Part H, since they are often the first professionals with whom families have contact.

A series of ten focus group discussions were held with health professionals in five states. The states (Colorado, Hawaii, Maryland, North Carolina, Ohio) were selected for their geographic and cultural diversity and leadership shown by policy makers and service providers in meeting the needs of children with disabilities and their families.

Health professionals were nominated in each of the states through recommendations of professionals and parents who were involved in programs for young children with disabilities. Those who were recommended were invited to participate by CPSP staff in focus group sessions. The meetings were open-ended and CPSP staff encouraged the presentation of all significant issues related to provision of services. A court reporter recorded and transcribed each discussion.

Out of these open-ended discussions emerged several themes that seemed to have implications for policy implementation in the states. The topics on which the discussions focused transcended state and regional boundaries, moreover, and were national in scope. Each of these themes will be presented in a brief report.

This report describes a view of the role of service coordinator. That view is based on an analysis of data obtained from the focus group discussions conducted with nurses and physicians.

Background

In 1988, a national conference on the participation of physicians in the implementation of Part H of P.L. 99-457 (now referred to as IDEA) was co-sponsored by the American Academy of Pediatrics (AAP) and the U. S. Office of Maternal and Child Health (MCH). Conference participants included representatives from each state's AAP chapter, as well as nationally recognized health policy experts affiliated with the AAP and with MCH. The goal of this conference was to develop a framework to guide strategies to be used at the federal, state, and local levels. These strategies were designed to ensure participation of primary care physicians in the implementation of this new legislation.

The goals and recommendations of this conference suggested a desire on the part of the health community to play an active role

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in providing services to families with young children who are developmentally delayed. In a report (American Academy of Pediatrics, 1988) developed from the AAP conference described above, the participants recommended, for instance, that primary care physicians participate actively in child find, assessment, and development and management of individual family service plans (IFSP). Physicians were urged to be knowledgeable of P.L. 99-457 and of their state's program of participation in this legislation, accessible in serving children with developmental disabilities and their families, and prepared for the role of acquiring necessary professional skills and knowledge.

With regard to the topic of "case manager," (service coordinator) the participants at the 1988 AAP conference made a distinction between the "medical manager" and the "case manager." It was noted in the AAP report that a physician could "serve in both capacities, at the family's request" (American Association of Pediatrics, 1988, p. 10). The medical manager's role was defined in the following way: "providing and/or ensuring the highest quality medical and health-related services, and functioning as an advocate for comprehensive services for infants and toddlers and their families" (American Association of Pediatrics, 1988, p. 10). Although limited to health related aspects of care, this definition is compatible with that provided in Part H of IDEA in which the service coordinator is defined as one "who will be responsible for the implementation" of a plan of intervention services that are "comprehensive, coordinated, [and] multidisciplinary." The law further specifies that the service coordinator be a professional whose discipline is most closely relevant to the needs of the child and family. In commenting on the selection of the overall case manager, it was observed that avoiding a conflict of interest in implementing a multidisciplinary service plan was critical. To accomplish this, it was recommended "that the case manager not be a provider of direct services to the child"(American Association of Pediatrics, 1988, p. 10). A definition of the overall case manager (service coordinator) was not otherwise explicitly addressed in this report.

According to an earlier study conducted by CPSP (Anderson, et al., 1991), the service coordinator was identified in most states during the meeting held to develop the child's Individual Family Service Plan (IFSP). As the presentation and discussion of the analysis presented below suggests, however, health care professionals, including physicians, already may be actively involved with many of these very young children and their families prior to the first IFSP meeting. In the case of infants and toddlers with developmental delays, health care providers are often the primary contact with professionals that families experience and are the primary source of identification and referral (Hanft, 1988). Particularly for the infant and toddler group, recognition by developers of policy at the federal, state, and local levels of ways in which involvement already occurs may have an impact on the implementation of this crucial legislation.

Findings

The health care providers who participated in the focus groups identified the role of service coordinator as the key to a family's successful entry to, and maintenance within, a family-oriented system of multi-disciplinary services including health care. Analysis and synthesis of actual experiences related by health care professionals resulted in the following description of the service coordinator as one who responds to the needs of the family while recognizing the family's own resources and abilities; possesses knowledge of community, programmatic, and financial resources; understands ethnic and socioeconomic diversity; and communicates with parents and professionals.

This coordinator of care may be a nurse, who works out of a public health agency, hospital, or doctor's office. The role also is filled by physicians, physician assistants, or even staff workers within a physician's office. Many of the physicians and nurses in our sample readily related to demands of the role of service coordinator as a natural extension of their medical responsibilities. At the same time, they pointed out that patients and their families who require coordination of multidisciplinary services consume inordinate amounts of time.

Three models of service coordination, which varied in terms of the degree of severity of the child's need for intervention and services, were suggested by the analyses of the data. At one end of the spectrum was the medically fragile child for whom the physician often managed the care and treatment, while at the opposite end of involvement the physician served as a medical consultant on a multi-disciplinary team. In the mid-range of involvement was a model of service coordination in which the physician served as a "medical manager" (American Academy of Pediatrics, 1988) while another professional (e.g., nurse, social worker) provided coordination of multidisciplinary services. Each model is discussed below and examples from the data are provided.

Physician as coordinator. Children who are identified as developmentally delayed in the age group targeted by Part H of IDEA often have impairment that is moderate-to-severe. Such impairment, moreover, likely includes physical abnormalities and medical complications, often of a life-threatening nature. Not only is a physician the initial professional who the child and family encounters, but also is the professional with the greatest involvement. Situations of a complex medical nature, which require the involvement of multiple medical sub-specialties, may necessitate that a physician serve as coordinator of services:

> A social worker as a case manager, [with] someone who does have a medical problem, plus a developmental problem, is in no position to say no to a specialist. It takes a physician to be able to stand up to ... other physician subspecialists. The nonphysician case manager is at a serious disadvantage. (Pediatrician in a tertiary care/teaching hospital)

The physicians and nurses who were interviewed focused on the needs of infants and young children with severe disabilities and with medical complications. These were the children with whom they described intense professional involvement and for whom they expressed a professional responsibility to serve in the capacity of coordinator of services. Except for cases that presented highly complex medical problems, most physicians who participated in these discussions did not seek this role.

Physician as medical coordinator. In situations where a child's disability required continued involvement from subspecialities within the medical community, as well as from professionals in allied health fields (e.g., physical therapy, speech pathology) or education (early intervention), a two-tiered model of service coordination was suggested.

The primary care physician coordinated the efforts of physicians who were providing subspeciality expertise and provided many decision-making functions:

> The case manager physician decides what other referrals need to be made: speech and hearing, ophthalmology, neurology. And then ... the evaluators come together with the case manager and discusses the evaluation of the child. Then the case manager ... talks to the parent about the evaluation and recommendations. (Pediatrician in private practice)

Another professional (e.g., early interventionist, nurse, social worker), in cooperation with the physician, handled the operational coordination of services among professionals, among other agencies and programs, consulted with the family, and assisted with paper work (e.g., reimbursement forms, referrals, feed-back):

> I've got a child associate who works with me.... She's got the training ... to have most of [case management] collated (Pediatrician in private practice)

This form of service coordination appeared to be, in fact, the most prevalent type for the age group, birth-to-three.

The major problem in providing a service coordinator is, of course, funding:

> I can't afford to have a social worker in my practice ... (Pediatrician in private practice)

> And we begged and pleaded and screamed to the legislature not to cut the funding for those [service coordinators], but it happened anyway. ... And when there's nobody else to do it, it falls back to the pediatrician. (Pediatrician in private practice at a tertiary care hospital)

Most young children with developmental delays are not classified as medically fragile, nor do they require intensive medical treatment or hospitalization. The physicians did report, however, that families continually seek out the advice of health professionals, even on topics not specifically related to matters of physical health (e.g., social-emotional development, early intervention). Several reasons for this phenomenon were suggested during the focus group discussions. One, physicians were often the first type of professional who assisted the family. The primary reason expressed, however, was that physicians provided a high degree of constancy or continuity, because they have a lower rate of professional attrition and mobility than do many other types of human service providers. Lower salaries, as an underlying cause of higher attrition and mobility among non-physician, human service providers, was a source of concern that was expressed in these discussions.

Physician as consultant to a multi-disciplinary team. In cases where the child's disability is mild or less medically complex, the physician's services may be best described as a consultant to the intervention team:

> My other hat is I work with the school system ... I meet with them four or five times a year and we go over problem handicapped individuals of all sorts. (Pediatrician in private practice and at a tertiary care center)

> I consult six times a year for Handicapped Children's Program [in a rural part of the state]. (Pediatrician in private practice)

In these cases, the coordination of the responses to needs of families was seen as best met by a social worker or public health nurse, with the physician providing medical treatment, and advising or consulting on an-as-needed basis.

The model in which a physician serves a member of and consultant to an interdisciplinary team may be the primary one used with children of school age. Our data analyses, which were based on more medically involved children, suggested that it was less widely used than the other two models with infants and toddlers.

While these models are presently utilized, these descriptions do not suggest a well-developed system of services. Rather, these models are organizational devices put into place by individuals and by small groups of health providers and families in an effort to deliver appropriate services.

Implications

In Part H of IDEA, emphasis is placed on the interaction between the families of children with developmental delays and professionals from among a wide range of disciplines. The law recommends coordination and integration of services through the efforts of the service coordinator who is to be identified at the time of the IFSP meeting.

Analyses of data collected from health care providers in the present study suggest that there are efforts already in place to assist many families in the critical area of service coordination. While these efforts are not as systematic as called for by Part H, they do represent the attempts of many professionals to provide a rational service plan. The fragmented efforts of coordination currently in place provide strong support for the need to develop a system of service coordination for these families.

For example, the data obtained through these discussions contained numerous

descriptions of infants who were "graduates" of neonatal intensive care units (NICU) located in tertiary care centers. In an effort to provide transition to a home environment for medically fragile infants, tertiary care centers often develop outpatient clinics. These outpatient clinics are staffed with service coordinators (e.g., nurses, social workers) who are responsible for interacting with families, assembling the requisite health, allied health, and early intervention professionals for evaluation and treatment, coordinating communication among professionals and between that group and parents, and convening conferences for the purposes of planning and interpretation between parents and professionals.

In the focus group discussions which CPSP held with health professionals, infants and toddlers with developmental delays characterized as severe were given great attention. While severely delayed or disabled, medically fragile children may represent only a subgroup of the population of children with disabilities, it likely constitutes a significant portion of that population and is a group that requires extensive expertise of a highly specialized, medical nature. Moreover, children with developmental delays in this age group (0-3), regardless of severity, are most likely to be initially identified and referred by health professionals (Hanft, 1988).

Recommendations

Interpretation of these findings suggest some recommendations for those charged with development of policy. One, the Interagency Coordinating Council might examine their state's policy directives to see if the policies related to service coordination sufficiently takes into account infants and toddlers who are most severely impaired. Given that Part H is directed toward provision of services to children who are in that range, birth-to-three, those with severe impairment or significant medical involvement likely will constitute a portion of eligible children.

Another area of critical need relates to specific allocation of funds for the position of service coordinator. This position is critically needed at all levels of provision of multidisciplinary care, but nowhere is the need more critical than for the families and children who are targeted by Part H. Yet, most insurers, including Medicaid, do not reimburse for time spent in care coordination efforts.

The states must plan and implement a system of service coordination for infants and children with disabilities and their families. It is a service needed by the children, their families, and the professionals, and the law requires it. The point stressed in this report is that policymakers consider existing processes and strategies. While present strategies are not systemic and may exist largely for a subgroup of children, the most severely impaired, such consideration could increase the effectiveness of a newly implemented system and minimize the disruption experienced by families and children.

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